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Part 0: Preamble

**Patterns, dynamics and influencing factors of Disclosure of HIV
status among women and men living with HIV in Cape Town,
South Africa**

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Declaration

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ABSTRACT

The aim of this study was to explore and examine the patterns, dynamics and influencing factors of HIV status disclosure among men and women at ARV clinics in low-income area clinics in Cape Town, South Africa and highlight areas for intervention and counselling improvement.

The specific objectives were to:

- Understand the factors that are associated with disclosure
- Explore factors that constrain/promote disclosure of HIV status
- Explore who people disclose to and why?
- Investigate what impact positive/negative reactions may have had on one's health and hopefulness of living with the virus.
- Make recommendations on how to address disclosure in support and treatment programs for people living with HIV.

This is a sub-study of a larger study to determine the effectiveness of reproductive health interventions in 4 clinics in Cape Town. This sub-study makes use of the first two sets of interviews out of a total of 3. This was a cohort study design with structured interviews and patient exit interviews. Data were collected between September 2007 and December 2008 in the four clinics. Ethics approval was granted by the Health Sciences Faculty Research Ethics Committee - REC REF: 429/2006.

Given the constantly changing nature of HIV in South Africa, tracking changes in the dynamics of disclosure over time is important, rather than relying on 'snapshot' perspectives. Analysis was foregrounded in global and Sub-Saharan African trends to draw out specificities from the South African context. The study concluded by highlighting gaps for further research and practical implications for the future of HIV prevention, support, care and treatment programming

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PART A: Protocol

I. Introduction

There is an extremely high prevalence and incidence of HIV in South Africa, coupled with relatively wide ranging access to anti-retroviral treatment (ART). As a result, many point out that an HIV positive diagnosis is transitioning from a 'death sentence' to a 'manageable illness' similar to other chronic conditions such as diabetes and high blood pressure. In this climate of high HIV prevalence and increasing numbers of people living with HIV (PLWHA) on ART, little is known about the changing dynamics of disclosure in this environment. This study aims to contribute towards filling this gap in knowledge.

Complexity of Disclosure

Some studies in South Africa point to a high overall level of disclosure of HIV status. For example, in one study in Soweto, ninety percent of those interviewed reported having disclosed their HIV status to at least one person in their family (1). However, many people living with HIV in their study had nevertheless, not disclosed their HIV status to their sexual partners. They concluded that this was a result of the relatively high proportion of their study respondents being "women in a male-dominated society where culturally based gender differences and personal power could explain some of this non-disclosure" (1). A number of other studies similarly point to gendered dynamics of disclosure, with women being less willing to disclose to an intimate male partner compared to men (2-4). These studies report that women were

more likely to fear that their economic and physical wellbeing would be jeopardized as a consequence of disclosing their HIV status to a male intimate partner (2,4-7). However, other studies have shown no significant difference in the HIV status disclosure to an intimate partner among heterosexual men and women (6). Interestingly, some research indicates that both men and women prefer to disclose to a female family member (2, 3).

Despite high levels of HIV prevalence, stigma is still perceived to play a major role in how those who are newly diagnosed perceive their HIV positive diagnosis. This is illustrated by how HIV status is communicated or not communicated to the people in their lives. For example, a recent working paper released by the Centre for Social Sciences Research based on data collected in townships around Cape Town demonstrated high levels of disclosure by PLWH to people within their individual households (5). However, this contrasted with low levels of HIV disclosure by PLWH to people within the general population. The study indicated that, “disclosure was not only met with positive and supportive responses from household members, but that it...shifted over time as individuals became more aware of the prevalence of HIV, and started to dissociate the virus from conceptions of promiscuity and death” (5). The authors problematise disclosure and describe it as a complex process. Their findings demonstrate that the barriers to disclosing are mainly eroding at the household level. Both the changing nature and high prevalence of the disease appears to have had an impact on this changing norm (5).

Dynamics Related to Disclosure and Non-Disclosure

Given varying levels of stigma around HIV, disclosing one's status or information that may lead someone to come to an HIV positive conclusion, has several potential risks and benefits which act as influencing factors to disclose. Those who have studied disclosure mention that people go through a 'cost-benefit analysis' before they disclose, weighing up the potential risks and benefits (2). The risks could include abandonment, physical violence, and feelings of shame, worry, fear and rejection. The benefits to disclosure may involve support, acceptance, changes to sexual risk taking behaviour and encouraging their sexual partners to seek information, testing and treatment (8).

As mentioned above, some studies have found that decisions related to disclosure and non-disclosure tends to balance a need for social support with the potential for social rejection (3). Disclosure at a community level has been found to be highly dependent on the broader sociopolitical context (2). In settings where there is a high level of knowledge and institutional support there has been found to be a correspondingly high rate of disclosure and openness about one's status. For example, one qualitative study in South Africa highlighted this in examining disclosure differences between two communities, Mbekweni in the Western Cape and Umzimkhulu in KwaZulu-Natal. While the communities were different in terms of geography, one was in an urban and the other in a rural area, culturally they were similar in that the majority of the populations in both communities were of Xhosa ethnic origin (2). Not surprisingly, in the rural community of Umzimkhulu there was relatively little institutional support for

PLWH compared to the urban community of Mbekweni, where there was relatively high institutional support, including HIV related non-governmental organisations, ART treatment activists and health system support for PLWHA (2). The authors' concluded that a wider sociopolitical context that is institutionally supportive of PLWH facilitates ease of disclosure and decision-making with respect to HIV status. They further point out that this is most effective when coupled with the existence of HIV interventions that promote increasing levels of HIV disclosure (2). These findings may link to this study context in Cape Town and I will explore whether similar factors operate in facilitating disclosure in this sub-study.

II. Justification

Little is known about the patterns, dynamics and complexity of HIV status disclosure and its influencing factors among people living with HIV in Cape Town, South Africa. Despite an acknowledgement of stigma playing an instrumental role in disclosure of a person's HIV status, there is very little information on what other factors interact in influencing the decision of PLWH to disclose their status. As people test positive for HIV, there is a need for increased understanding of the individual, interpersonal and wider socio or political factors influencing the decision making process in disclosure or non-disclosure of HIV infection. Gaining insights into these little understood areas by exploring attitudes, beliefs and practices is important in informing HIV care and treatment programs in supporting PLWH in their HIV status disclosure decisions.

The proposed research will therefore examine the patterns and dynamics of disclosure of HIV status among men and women in Cape Town in order to provide up to date information on how to better understand the pressures, support and challenges facing PLWHA and facilitate living positively with the virus. The proposed study will use in-depth interviews to explore the factors that play on people's decision-making in relation to disclosing one's HIV status, to whom and why, over a period of six months through baseline interviews and follow-up interviews with the same participants. The study will thus illustrate how various factors influence important decisions on sharing one's status and what impact treatment and care interventions have on their decision-making process and how these things change over time.

III. Research Question

What are the patterns, dynamics, practices and influencing factors regarding HIV disclosure by HIV positive people in low-income clinic based settings in Cape Town?

IV. Objectives

The objectives of the proposed study are:

- To understand the factors that are associated with disclosure
- To explore factors that constrain/promote disclosure of HIV status
- To explore who people disclose to and why?
- To investigate what impact positive/negative reactions may have had on one's health and hopefulness of living with the virus.

- To make recommendations on how to address disclosure in support and treatment programs for people living with HIV.

V. Methods

This proposed qualitative research constitutes a sub-study of larger study that was conducted between March of 2007 and August 2011 by the Women's Health Research Unit at the University of Cape Town in South Africa and the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University in the United States. The study was in collaboration with the Western Cape and City of Cape Town Health Departments. The overall findings from phase one of the study which comprised formative qualitative research, were intended to guide the development of a multi-level structural intervention integrating sexual and reproductive health issues for HIV+ women and men and improve relevant counseling and services for women and men clients living with HIV.

Rigor was maintained in data collection and analysis through quality assurance and data analytic methods. All elicitation data was taped via digital recorders and sent password-protected to both study principals to engage in timely discussions with field workers and supervisors on the ground. The creation of standardized interview guides, monitoring of interviews and training of field workers and translators ensured the rigidity of the data was maintained. Limitations in the analysis include my entry into the project after data collection took place which will affect the way in which analysis and interpretation of the data is carried out.

It is important to note that I as the researcher was not involved in any data collection, design of interview guides, deciding on tools or supervision of data collection of any kind. As such, there are certain advantages and disadvantages. Some might argue that an advantage to this is that it gives me a slightly more 'objective' frame of reference in data analysis. However, drawbacks also abound, as I may not have caught onto context and situation specific complexities that would have only been apparent if I had been involved in the data collection, design and supervision. These complexities could have better served the research process and created a more holistic understanding of the data.

VI. Study Design

The main study was a cohort study design. This sub-study will draw on two sets of qualitative interviews conducted with study participants that formed part of this formative phase of the overall study. These include the initial interviews conducted between September to December 2007 and the first follow-up interviews conducted with study participants between July and December 2008 after the intervention was implemented. Participants had HIV tests within the last year but were in the pre stage of ARV treatment i.e. undergoing literacy and counseling before initiation. The proposed research will analyse already collected data from the qualitative component of the interviews conducted as part of the overall formative phase of the study. The specific focus of this sub-study will be participants' views, experience and practices around HIV status disclosure.

Study Population

Participants for the overall study and this sub-study were drawn from four HIV care clinics (pair-matched on size [medium and large], [HIV+ caseload], geographic location and gender/racial composition of clients). Participating clinics serve clients with a demographic profile likely to be seen in other HIV care clinics throughout Cape Town's public sector system, and thus will reflect typical background characteristics of HIV+ clients attending such care.

Participant sampling, eligibility criteria and interview procedures

In each clinic, study staff systematically approached every third client seated in the waiting area. Participants had entered into the public sector HIV care system (but had not initiated ARV treatment). Eligibility criteria included (1) HIV+; (2) 18 years or older; (3) able to consent and participate in the interview; and (4) willing to have the interview audio-taped. Exclusion criteria included gross evident cognitive dysfunction that would preclude the ability to consent and participate in the counseling.

The objectives and procedures of the study were explained and the informed consent process was initiated with interested clients. Interviews were scheduled at this time, or conducted as close as possible to the day of recruitment. Qualitative in-depth interviews were conducted by experienced qualitative interviewers who were the same sex as participants, in the participants' first language (Xhosa) or in English if the participant preferred. The final sample size was 26 HIV-positive, Xhosa-speaking women

and 26 HIV-positive Xhosa-speaking men. Interviews were audio-recorded, transcribed and if in Xhosa, were translated into English.

Study Instruments

Interview guides were semi-structured; open-ended and used probes to ensure that key issues were covered in adequate depth. The interview guide explored the following key areas: disclosure of HIV status, impact of HIV on their lives, desire for parenthood, changes in sexual functioning due to HIV status, reproductive decision-making, approaches to safer conception in the context of HIV; views on interventions to support safer conception for HIV+ people; and opinions about integrating components of reproductive health care into routine HIV care. In this sub-study, only the issues explored with respect to disclosure of HIV status, the dynamic and process of disclosure and the factors influencing disclosing will be explored.

VIII. ANALYSIS PLAN

Data management

Data will be managed using the Nvivo software qualitative data management package

Data Analysis

Analysis of the qualitative interview data will first be guided by the “grounded theory” approach described by Strauss (9). First, interview narratives will be reviewed to identify analytic and thematic categories that emerged in response to the interview questions and relate to the main outcome variable specified, disclosure. Since open

coding of the data will allow for the emergence of new constructs related to disclosure, this will ensure that I am not solely limited to the initial variables mentioned. I will code the interview transcripts for major categories and sub-categories within the overall theme of disclosure. I will explore commonalities and differences within and across participants and search for outstanding cases. The analysis will be applied to all transcripts using Nvivo software designed for systematic management and analysis of qualitative data. As mentioned, based on exploratory analyses, additional domains will be added and some excluded.

Other frameworks that have been formulated around disclosure of HIV status research will also be explored for their utility in this study. One such example is Campbell and Foulis definition of stigma as a starting point, which describes it as a ...system-justifying function to validate the status quo and avoid change, which results in othering wider social interests. Stigma is an embedded and collectively negotiated set of social representations and practices, which are constructed, reconstructed and reproduced or challenged in the on-going interactions of communities of peers (10).

Intertwined, levels of stigma directly determine both the possibility and mode of disclosure. Many see the issue of HIV status disclosure of vital importance to the success of the support, care and treatment programs that promote people living positively with HIV. The nuances of disclosure are often less studied and are usually directly related to the corresponding type of stigma associated with disclosing. One study in Johannesburg aimed to add to this knowledge gap by analysing various dimensions of stigma and their

relationship to disclosure (11). It concluded that disclosure can be either voluntary or involuntary and the mode of disclosure as being either direct or by proxy, ie- one's actions simply implies HIV positivity (i.e. seeing someone at the ARV clinic by 'proxy' discloses one's status) (11). This data may be used as a form of categorization in the pre-analysis phase depending on the outcomes of the grounded theory approach.

IX. ETHICS

The study protocol, interviews, and consent forms were reviewed and approved by the Institutional Review Board at the New York State Psychiatric Institute and Columbia University Department of Psychiatry, and the Health Sciences Faculty Human Research Ethics Committee at the University of Cape Town. An information sheet with the aims of the research was provided to all interviewees before the proceeding with interviews. Before each interview, written informed consent was obtained from each participant. Interviewees were informed that their answers were anonymous and confidential. It was made clear to participants that they were free to withdraw from the study at any time without any negative consequences. Interviewees were advised that the interview would be recorded and the data will be used towards the study. They were informed that all recorded interviews would be kept in a safe, locked cabinet where only the researchers would have access. Once all data has been translated and transcribed, the original interviews would be deleted. After each interview, participants were provided with a chance to ask questions and provide feedback. All respondents were compensated financially for their time and transport, as follows: participants were paid the equivalent of \$5.50 for the initial interview and \$6.50 for the first follow-up

interview. All participants completing interviews were debriefed and given appropriate referrals when requested or indicated.

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PART B: Literature Review

1.1 Search Strategy and Objectives

The objectives of this literature review was to explore the rates, dynamics and outcomes of disclosure of HIV status in South Africa and similar environments to preface the analysis of interview data on the dynamics of disclosure in Cape Town. This review included both qualitative and quantitative studies. The review was restricted to articles and documents published in English since 1995. PubMed, JSTOR, and Google Scholar were searched in addition to hand searching the bibliographies of selected peer reviewed articles. Key words for the search criteria included 'Disclosure', 'Dynamics, Patterns, Rates', 'South Africa', 'Cape Town and 'HIV treatment'. Abstracts of retrieved articles were read and if they were pertinent to the research question, full texts were then retrieved. Due to the dearth of information related to the topic, inclusion criteria were broad so as to ensure a comprehensive understanding of the topic.. In addition to conducting a targeted web-based search of reported literature from select sites including Health Systems Trust, the World Health Organization (WHO) and the Joint United Nations Programme on HIV AIDS (UNAIDS) to retrieve information on disclosure guidelines and interventions and the general search.

1.2 Problem Statement

The most recent estimates indicate that the number of people living with HIV and AIDS (PLWHA) in South Africa is 5.5 million (1). Of these, approximately 1.5 million

are now receiving antiretroviral therapy (ART) (2) an increase of 250% since 2006, and provision of ART resulted in an estimated 700,000 life-years gained in 2010 (1,2). In 2010 an estimated 900,000 were still in need of anti-retroviral therapy (3). However, as criteria for going onto public sector ART were changed in line with WHO criteria in late 2011, the current number needing treatment still needs to be ascertained. As a result, many point out that an HIV positive diagnosis is transitioning from a 'death sentence' to a 'manageable illness' similar to other chronic conditions such as diabetes and high blood pressure and indeed the annual number of AIDS deaths had decreased by 2011 (2). In this climate of increasing prevalence due to people living longer with HIV but a decreasing, yet still high incidence of 1.7% (4), little is known about the dynamics of disclosure. Therefore, this study aims to contribute to filling this gap.

Stigma still plays a major role in how those who are newly diagnosed perceive this diagnosis and how it is communicated or not communicated to the people in their lives. Therefore the importance of disclosure cannot be underestimated or understated. Studies link disclosure with increased adherence and beneficial health outcomes. Not only this, there is also an acknowledgement from experts that disclosure leads to the overall emotional wellbeing of PLWHA (5-7).

A recent working paper released by the Centre for Social Sciences points to high levels of disclosure within individual households contrasted with low levels of disclosure at a community level. The study indicates that, "disclosure was not only met with positive and supportive responses from household members, but that it...shifted over

time as individuals became more aware of the prevalence of HIV, and started to dissociate the virus from conceptions of promiscuity and death” (8). Disclosure is a complex process for which the negative effects of stigma still discourage disclosing and living openly with the virus. However, their findings demonstrate that barriers are slowly eroding. Presumably, both the changing nature and high prevalence of the disease has had an impact on this changing norm (8).

Given varying levels of stigma around HIV, disclosing one’s HIV status has several potential risks but also potential benefits which act as factors influencing the dynamics of disclosure. Potential risks include abandonment, physical violence, and feelings of shame, worry, fear and rejection. The benefits to disclosure may involve support, acceptance, access to appropriate treatment, changes to sexual risk taking behaviour as well as to encourage their sexual partners to seek information and testing (9). Stigma around disclosing is complex and dynamic in South Africa. It is tied to the country’s history of access to ART, which is fraught with conflicts, court challenges and at times militant social movements to demand treatment. This has created a rights-based discourse around access to treatment and access to health care more generally but has this translated into personal and institutional modes of disclosure? Appraising the changing reasons behind HIV disclosure will enable more effective and contextual responses in treatment and adherence programs.

1.3 Rates of Disclosure

Some studies in South Africa point to a high level of overall HIV status disclosure. In one study in Soweto, ninety percent of those interviewed reported having disclosed their HIV status to at least one person in their family (13). However, the study authors found that many people living with HIV in their study had not disclosed their HIV status to their sexual partners. They concluded that this was a result of the relatively high proportion of their study respondents being “women in a male-dominated society where culturally based gender differences and personal power could explain some of this non-disclosure” (13).

A study tracking disclosure patterns in two antenatal clinics in Tshwane, an urban area of South Africa, identified 59% of women disclosing their HIV-positive status to at least one person outside of the healthcare setting, compared to 41% reportedly not disclosing. Of these women who had disclosed, 11.3% had disclosed to two people and 7.2% to three or more people (12). Of those who disclosed, only 14.6% disclosed to people outside of their immediate family (12). A structured review of over 15 studies on disclosure of HIV status in developing countries revealed that rates of disclosure among women ranged from 16.7% to 86%. Notably, data from these articles point out that as the length of time since diagnosis increases, the rate of disclosure also increases (13).

1.4 Factors Influencing Disclosure

Studies demonstrate conflicting results when examining the effects of psychosocial support and their influence on disclosure. One might assume that higher amounts of social support such as HIV/AIDS support groups and VCT available at the clinic level would lead to a higher disclosure rate. However, reviews of VCT literature in Africa suggest that the evidence of this assumption is 'far from optimistic' (14). Data taken from Tanzania shows disclosure rates ranging from 16-27% in varying VCT contexts throughout the country. Alternatively in a different review of literature, home-based VCT models in Zambia and South Africa were shown to be quite effective with higher rates of disclosure 'success' (15). Similarly, research on the link between support groups and disclosure are favourable (16). In one such study from Kenya support groups were found to give women the confidence they needed to disclose to others outside their group and provide them with the emotional support to cope with many negative outcomes of disclosing (16).

In one qualitative study with a large sample size of upwards of 300 interviews, there was incredible insight into HIV disclosure which pointed out that decisions related to disclosure and non-disclosure tend to balance a need for social support with the potential for social rejection (10). The authors described this as a type of 'cost-benefit' analysis or appraisal of the factors related to the outcomes of disclosure (10). This has

been heavily documented in disclosure related research in southern African settings (10-12).

Disclosure, especially at a community level has been found to be highly dependent on the sociopolitical context (11). One qualitative study in South Africa highlighted the disclosure differences between two communities, Mbekweni in the Western Cape and Umzimkhulu in KwaZulu-Natal. While the communities were different in terms of geographic location in that one was urban and one was rural, they were culturally similar in that the majority of the populations in both communities were of Xhosa ethnic origin (11). In the rural community there was relatively little support compared to the urban community in the Western Cape where there was relatively high institutional support, including NGOs, treatment activists and health system support (11). The authors' conclude that a wider sociopolitical context that is institutionally supportive of PLWHA facilitates ease of disclosure and decision-making with respect to HIV status. They further point out that this is most effective when coupled with the existence of HIV interventions that promote increasing levels of HIV disclosure (11).

1.5 Disclosure Dynamics

Like many social processes, disclosure of HIV infection is a process that does not necessarily follow predictable patterns. In a World Health Organization (WHO) review that focused on four studies of disclosure dynamics, the most common barriers to disclosure by women were fear of abandonment, rejection and discrimination, violence, upsetting family members, loss of economic security and accusations of infidelity (17).

One very recent study on disclosure of HIV status to sexual partners in Cape Town supports the argument that HIV- related stigma (both perceived and experienced) is an important barrier in disclosing one's HIV status, especially among steady sexual partners (18). The research further confirms that "fear of losing or damaging a steady relationship, coupled with perceived stigma of HIV, likely diminishes the likelihood of disclosing one's HIV status to a steady partner" (18). This insight into disclosure in low-income settings in Cape Town reveals one aspect of disclosure dynamics among sexual partners.

Research into the gendered dynamics of HIV in South Africa has revealed a better understanding of the differences between men and women in terms of fears and experiences of HIV- related stigma within sexual and social relationships. The WHO review on gendered disclosure found that younger women were significantly more likely to disclose their HIV status than older women, as did women of lower-socioeconomic status compared with women of higher socioeconomic status (18). As an example, in a recent Cape Town based study examining HIV/AIDS testing and disclosure, women described disclosure as a difficult process due to the fact that they feared being blamed for being the one to bring HIV in the relationship. Not only this, authors of this study noted that disclosure had different and significant consequences on men and women's health and general wellbeing (19). For example, the study problematises the 'responsibility of knowledge' and its effects that falls on women due to the fact that many women learn of their HIV status first due to testing at antenatal clinics and their likelihood to access health care more frequently than men (19).

Two South African qualitative studies on disclosure indicate that men and women prefer to disclose to a woman family member and that women are less willing to disclose to their partners compared to men (10, 11). However, an Ethiopian study examining the gender differences in HIV disclosure showed no significant difference in the proportion of HIV status disclosure among men and women (20). It is for this reason that this sub-study will explore the contextual nature of barriers and motivators for disclosure including but not limited to gender-related factors influencing disclosure.

1.6 Outcomes of Disclosure: How does this impact lives/treatment/adherence?

While the WHO review identified that the majority of outcomes reported post-disclosure were positive, there was still a range of negative outcomes experienced by between 4-28 % of respondents (17). These negative outcomes aligned closely with factors influencing disclosure that mitigated women's willingness to disclose their HIV status, namely fears of blame, abandonment, violence, anger, stigma and depression (17). In the Tshwane study, women who disclosed their HIV-positive status to their partners reported that their disclosure was met with four different types of reactions. The three most common were negative reactions, including denial and disbelief, an overtly emotional reaction' and shock (21). A minority (11%) reported that their partners' reacted with support and acceptance. Conversely, for women who disclosed to family and relatives, over 50% reported that their disclosure was met with reactions were of support and acceptance (21). Twenty-three percent of women told their parents, while the same proportion told 'other' family members because they reported them as a 'supportive/trusting relationship' (21).

The 2011 Vu et al study conducted in Cape Town also found a strong positive association between HIV disclosure and entry into an ART program and they conclude that this may be a result of the health benefits of ART, which can result in reducing perceived stigma, leading to more confidence in disclosing (18). This finding links particularly well with the aim of this study which is to chart the dynamics and influencing factors present in a setting with high levels of PLWHA on ART. Additionally, this conclusion is corroborated with previous analysis that ART positively alters sexual risk behavior (18).

1.7 Limitations of Existing Studies

With the largest rollout of ART in the world, South Africans living with HIV have relatively wide ranging access to treatment, particularly in urban areas. In a recent report, Christopher Colvin of the Centre for Infectious Diseases and Epidemiological Research at the University of Cape Town points out that “Many of the dramatic developments in the earlier history of the HIV epidemic were driven by a focus on HIV’s “acuity” rather than its chronicity...especially in Southern Africa” (22). This change to chronicity coincides with a major shift of norms and the meaning of disclosure to others that a person is living with the virus. There is a need for research into this changing, dynamic environment where stigma’s role in disclosing one’s status is diminishing. The rights-based culture related to HIV and ART continues to play a major role in shifting the norms of living with HIV by promoting social acceptance and awareness but what is the lived experience of this ‘culture’ around HIV/AIDS?

While there is an increasingly large body of research into the gendered dimensions of disclosure from a women's perspective, particularly pregnant women there is a gap relating to men's experiences of disclosure. Men as a subject and focus of social science research and intervention are an emerging area in South Africa and insight into men's experiences of disclosure is greatly needed. There is a need for further research to deepen our understanding of the processes, dynamics and influencing factors in terms of disclosure as it relates to men.

These are emerging research areas in South Africa that require timely, qualitative inquiry in order to begin to capture their complexity. This study aims to provide insight into the gendered disclosure dynamics as they relate to men as well as whether the 'chronicity' of HIV has had an impact on disclosure dynamics.

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PART C: JOURNAL MANUSCRIPT

“...this thing is like a natural thing now.”:

Dynamics of HIV Disclosure among women and men living with HIV in Cape Town, South Africa

Abstract

This study examines the changing dynamics of HIV status disclosure among a sample of 57 HIV-infected men and women attending HIV clinics in Cape Town, South Africa. Despite high HIV incidence and prevalence rates in South Africa and massive ARV treatment availability, there is little research on the changing dynamics of HIV disclosure and associated well-being over time. Results include a high rate of inter-household disclosure. Over time, participants discussed a general hopefulness of living with HIV and compared it to many other chronic infections, pointing to the perception of HIV as a manageable illness. The findings support a positive prevention strategy that emphasizes increased access to ART, and behavioral and sociopolitical interventions for persons who are HIV-positive. Counseling should routinely address the dynamics, including gender dynamics, shifts over time and barriers slowly eroding to disclosure.

Keywords: HIV disclosure, HIV stigma, South Africa

Introduction

There is an extremely high prevalence and incidence of HIV in South Africa, coupled with relatively wide ranging access to anti-retroviral treatment (ART). The most

recent estimates indicate that the number of people living with HIV and AIDS (PLWHA) in South Africa is 5.5 million (1). Of these, approximately 1.5 million are now receiving antiretroviral therapy (ART) (2) an increase of 250% since 2006, and provision of ART resulted in an estimated 700,000 life-years gained in 2010. In 2010 an estimated 900,000 are still in need of anti-retroviral therapy (3). However, as criteria for going onto public sector ART were changed in line with WHO criteria in late 2011, the current number needing treatment still needs to be ascertained. As a result, many point out that an HIV positive diagnosis is transitioning from a 'death sentence' to a 'manageable illness' similar to other chronic conditions such as diabetes and high blood pressure and indeed the annual number of AIDS deaths had decreased by 2011 (2). In a context where an increasing number of people are living longer with HIV despite a decreasing but still high incidence of 1.7% (4), little known about the changing dynamics of disclosure, if any. This study aims to contribute towards filling this knowledge gap.

The importance of disclosure cannot be underestimated or understated. From a biomedical perspective, studies link disclosure with increased adherence and beneficial health outcomes. Additionally, from a psycho-social perspective there is an acknowledgement in the literature that disclosure leads to the overall improved emotional well being of PLWHA and lifts a burden from their lives (5-7).

Studies in South Africa point to a high overall level of disclosure of HIV status, especially in urban settings. For example, one study in Soweto revealed that ninety percent of those interviewed reported having disclosed their HIV status to at least one

person in their family. However, the study found that many people living with HIV in their study had nevertheless, not disclosed their HIV status to their sexual partners. They concluded that this was a result of the relatively high proportion of their study respondents being “women in a male-dominated society where culturally based gender differences and personal power could explain some of this non-disclosure” (8). A number of other studies similarly point to gendered dynamics of disclosure, with women being less willing to disclose to an intimate male partner compared to men (9, 10). Overwhelmingly, women were more likely than men to fear that their economic and physical wellbeing would be jeopardized as a consequence of disclosing their HIV status to a male intimate partner (9-13). However, one study did show no significant difference in the HIV status disclosure to an intimate partner among heterosexual men and women (12). Interestingly, some research indicates that both men and women prefer to disclose to a woman family member (10,11).

Despite high levels of HIV prevalence, stigma is still perceived to play a major role in some contexts and how those who are newly diagnosed perceive their HIV positive diagnosis. One study demonstrated high levels of disclosure by PLWH to others within their individual households in a Cape Town township. However, this contrasted with low levels of HIV disclosure by PLWH to people within the general population (14).

Given varying levels of stigma around HIV, disclosing sensitive information has several potential risks but also potential benefits which act as factors influencing the dynamics of disclosure. Some of the risks may include abandonment, physical violence,

and feelings of shame, worry, fear and rejection (15). The benefits to disclosure may involve support, acceptance, access to appropriate treatment, changes to sexual risk taking behaviour as well as encouraging their sexual partners to seek information and testing (15). Disclosure, at a community level has been found to be highly dependent on the broader sociopolitical context. In settings where there is a high level of knowledge and institutional support there has been found to be a correspondingly high rate of disclosure and openness about one's status (9).

Little is known about the patterns, dynamics and complexity of HIV status disclosure and its influencing factors among people living with HIV in Cape Town, South Africa. The study indicated that, "disclosure was not only met with positive and supportive responses from household members, but that it...shifted over time as individuals became more aware of the prevalence of HIV, and started to dissociate the virus from conceptions of promiscuity and death" (14). This indicates that over time, as HIV was perceived to be more common in the general community and less associated with death, disclosure rates increased at the household level. This demonstrates that while stigma is still a significant barrier to living positively with the virus, barriers may be slowly eroding at the household level. Both the changing nature and high prevalence of the disease appear to have had an impact on this changing norm.

Despite an acknowledgement of stigma playing an instrumental role in the willingness of PLWHA to disclose their HIV status, there is very little information on what other factors interact with the perception and/or experience of stigma in influencing

the decision of PLWH to disclose their status. As people test positive for HIV, there is a need for increased understanding of the individual, interpersonal and wider socio-political factors influencing the decision making process in disclosure or non-disclosure of HIV infection.

This study used in-depth interviews to explore the factors that play a role in PLWHA decision-making in relation to HIV status disclosure as well as to whom disclosure is usually made and the reasons for this. By examining the patterns and dynamics and influencing factors of disclosure of HIV status among men and women living with HIV attending public sector HIV care in Cape Town, this study provides insights on the pressures, support and challenges facing PLWHA with respect to disclosure of HIV status. Gaining insights into these under researched and dynamic social processes by exploring attitudes, beliefs and practices has important implications for informing HIV care and treatment programs in supporting PLWH in their HIV status disclosure decisions. In practice, these insights can contribute to treatment and care initiatives to promote disclosure while enabling PLWH to lead more fulfilling lives.

METHODS

Study Design and Participants

The aim of this study is to explore specific sections of knowledge gained from a larger cohort study that was conducted between March of 2007 and August 2011 by the Women's Health Research Unit at the University of Cape Town in South Africa and the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute

and Columbia University. The overall findings from phase one of the study which comprised formative qualitative research, were intended to guide the development of a multi-level structural intervention integrating sexual and reproductive health issues for HIV+ women and men and improve relevant counseling and services for women and men clients living with HIV.

This sub-study draws on these two sets of qualitative interviews conducted with study participants that formed part of the formative phase of the overall study. These include the initial interviews conducted between September to December 2007 and the first follow-up interviews conducted with study participants between July and December 2008 after initial implementation. Participants had HIV tests within the last year but were in the pre stage of ARV treatment ie. undergoing literacy and counseling before initiation. The study used previously collected data from the qualitative component of the interviews conducted as part of the overall formative phase of the study. The specific focus of this sub-study is on participants' views, experience and practices around HIV status disclosure.

Study Population

Participants for the overall study and this sub-study were drawn from four HIV care clinics (pair-matched on size medium and large in terms of HIV-positive client caseload, geographic location and gender/racial composition of clients). Participating clinics serve clients with a demographic profile likely to be seen in other HIV care clinics

throughout Cape Town's public sector system, and thus will reflect typical background characteristics of clients living with HIV and attending such care.

In each clinic, study staff systematically approached every third client seated in the waiting area. Participants had entered into the public sector HIV care system (but had not initiated ART). Eligibility criteria included (1) HIV positive; (2) 18 years or older; (3) able to consent and participate in the interview; and (4) willing to have the interview audio-taped. Exclusion criteria included gross evident cognitive dysfunction that would preclude the ability to consent and participate in the counseling.

The objectives and procedures of the study were explained and the informed consent process was initiated with interested clients. Interviews were scheduled at the health centre visit, or conducted as close as possible to the day of recruitment. Qualitative in-depth interviews were conducted by experienced interviewers who were the same sex as participants and in the participants' first language (Xhosa) or in English according to participants' preference. The final sample size was 26 HIV-positive, Xhosa-speaking women and 26 HIV-positive Xhosa-speaking men.

Interviews were audio-recorded, transcribed and if in Xhosa, translated into English. Data was managed with Nvivo software. Analysis of the qualitative interview data was first guided by the "grounded theory" approach described by Strauss (16). First, interview narratives were reviewed to identify analytic thematic categories that emerge in response to the interview questions and relate to the main outcome variable specified, disclosure. Since open coding of the data allowed for the emergence of new

constructs related to disclosure, this ensured that major categories and sub-categories within the overall theme of disclosure were raised. Commonalities and differences within and across participants and search for outstanding cases was also analysed. As mentioned, based on exploratory analyses, additional domains were added.

RESULTS

Initial Thoughts on HIV Diagnosis

Interview participants were asked what their initial thoughts and feelings were towards their diagnosis. This question foregrounded their willingness or unwillingness to disclose. While some previous research points to fatalistic and devastating feelings upon learning of diagnosis, this data suggests an HIV positive diagnosis was considered by many as manageable, especially over time. As one 27 year-old male respondent put it, "I just accepted the condition and I told myself that its just another disease like others; understand and it is like TB, and arthritis, understand, and some people end up having diabetes, so I told myself that this is like the same as diabetes and others if I just need to stick to my treatment there is nothing really..." The initial perception of the manageability of an HIV positive diagnosis was not universal. Others expressed shock, deep sadness and devastation upon learning of their condition. These feelings were compounded for women who found out about their status at the time that their baby was diagnosed with HIV or on the heels of a death of a partner or family member from HIV related illnesses. This speaks to the continued devastation HIV/AIDS is having on individuals and communities in Cape Town.

Processes of Disclosure

Disclosure is now widely recognised as a process, rather than a singular action (17-19). As such, it is very difficult to ascertain all of the factors at play retrospectively. Some possible steps include disclosure as a response to advice from health service providers especially combined with various support mechanisms present in many clinic settings for example. While not detracting from the challenges in doing so, and hesitancy in disclosing to non-family members, for many respondents in this sample there was a simple feeling disclosing one's status was 'the natural thing to do'. For all respondents, disclosure of HIV infection was not a once-off event but occurred through a series of processes and decisions over time.

The variation in the processes ranged from respondents who were actively engaged in disclosing and managing their diagnosis as well as those who took a more passive role, biding their time or disclosing by 'proxy'. By 'proxy' meaning that something else triggered disclosure such as severe weight loss, pregnancy or seeing a friend or relative at the HIV clinic. As one 35 year old woman put it, "I never felt I could tell any person, I remained for months knowing it alone and then I started talking about it just because I saw a person I had a relationship with here at the clinic and then I was able to disclose to my sister and I told her." Presumably, the comfort of knowing that someone she was close too was in a similar situation to her provided her with the courage to disclose her status and get some support.

Respondents had varying reactions to their diagnosis and reasons for disclosing. However, all but one respondent disclosed to at least one person and overall most respondents disclosed to a family member (usually a sibling) of the same gender and age range. However, the data indicated that disclosure in intimate relationships was much more complex, which may reflect the uncertainty about how a partner would react to news about the diagnosis, including potential fears about violence, loss of economic security, rejection, or abandonment. This may be a result of the perceived chronicity and manageability of the illness, which could act as a positive factor for women in these settings. This is in contrast to previous research that suggests women are hesitant to disclose to male partners given their reliance on men for economic support and fears that they may lose this (9-13). Our respondents did not highlight this as a major concern in these interviews.

Participants identified different ways they may have come to a diagnosis and subsequent decision to disclose their status. For example, one respondent mentioned that her co-workers noticed she was losing weight and had encouraged her to go to the clinic to treat her cold. After concern and empathy showed to her by her peers, she had less of a challenge disclosing to people in that setting.

In another case, the 27-year-old respondent reported that she and her family took on her diagnosis and that of her baby girl as a 'team' because the child was the main focus of care. At first, she simply disclosed to her partner and family immediately and was hesitant to tell her in-laws, despite their close relationship. However, her

sisters-in law eventually found out by proxy disclosure because she kept seeing them near the clinic. Despite her initial apprehension, her sisters in-law were supportive but advised her not to tell their parents because they would heavily criticise her. This may point to a trend indicating greater acceptability in a younger generation versus an older one.

The range of 'management styles' of HIV disclosure seemed to have a relational effect on the sentiments and feelings of people around them. These management styles changed over time, as is evidenced by the differences between the initial interview and follow-up. It seemingly represents an area of control and decision-making that is honed in on the range of acceptance and stigma in their surroundings and their continuing acceptance of this illness.

Strategies, Responses and Outcomes of Disclosure

Disclosure can be both a positive and negative experience. This section highlights some of the outcomes to disclosure. When comparing the initial thoughts and feelings upon diagnosis with the actual reactions of those to whom participants disclosed, while the majority of respondents initially cited a fear of rejection by loved ones, this was not borne out in the actual responses experiences. There were no reports of violence because of disclosure of HIV-positive status in this qualitative sample. Of the 24 respondents who disclosed their HIV-positive status to partners, 3 reported that they had experienced negative outcomes. One man who experienced a negative response stated that his partner went into a severe state of denial that both he and (possibly) she

had the virus. She repeatedly said she did not have it and that he must have acquired it from someone else. This reaction made him feel uncomfortable and as he put it, “it puts me at risk”. He did not elaborate on this point.

A 25-year-old woman described a different type of outcome to disclosure. After her boyfriend died of AIDS related causes, she had very little doubt that she herself was probably infected. After ‘dragging her feet’ for several months after his death she finally went to the clinic to be tested. Even after she received her HIV positive diagnosis she told no one for several months and kept it all to herself. After time had passed, she began disclosing to her sisters, one by one, who were not shocked at her status and offered supportive words and advice. After disclosing to her family, she began disclosing to individual friends and discovered that two of her closest friends had also been hiding their HIV- positive status for quite some time. The respondent said, “Yes I see it (disclosing) as important because ... when you meet with me you are free to talk to me because we are all the same (i.e. we are all HIV+) you see?”

Fears of wider social rejection was reflected in many interviews by respondents stating that the ‘best’ support is mainly found in families and the clinic environment. One 37 year-old woman pointed out, “The support I have found is support at the clinic; here in the community there are people who have it but its just that they don’t want to come forward so that we can support each other, so the support I’m getting is at the clinic and from my family.”

Gendered Dimensions of Disclosure

The majority of women interviewed stated that by disclosing their HIV status to either loved ones or health care professionals, they received not only support but also reassurance that they were still human beings capable of natural, 'normal' things. As one woman stated: "it is not meant that you shouldn't fall in love but make love responsibly, use a condom that's all, there's nothing that changes, its just to guide your life and continue with the treatment that is said you must use." Another respondent reported that her overall support actually improved. She reported that she got more support now from her mother and her sisters than she did before they knew of her HIV positive status.

Women disclosed more readily to their inner circles of friends, which may indicate gendered norms among female friends that facilitate disclosure. Some women experienced abandonment from their friends. Discussion of a positive diagnosis had an impact on their friend circle. As a young woman pointed out, "...others who acted like my friends...there is not a single friend that is next to me now, all of them left me and one that I had thought is so close to me she too left..." Many women perceived this type of social rejection as a result of being HIV positive. As another young woman pointed out in reference to this type of scenario, "...I told myself that I don't need a friend anymore like cherries (i.e. females), a boyfriend I also told myself I don't want at all." Some people found support despite these disappointments and supportive individuals encouraged respondents not to disclose to their friends. One woman reported her sister saying to her, "don't stress yourself telling other people outside because they are going to call you names ..."

Chronicity and Manageability of HIV in light of greater ART access

Perceptions of social support and acceptability were positively associated with the knowledge that 'HIV is not the end of life'. This reaction seemed to be fundamentally important to the wellbeing of most respondents. There was a vast difference between the initial shock and sometimes depression upon hearing of one's diagnosis to the reportedly 'life moves on' theme apparent in many respondents' decisions to disclose.

One woman disclosed her status to her aunt who commented on the current perceived commonness of HIV. She reported that her aunt was not shocked and said, "this is happening a lot to people, it is not uncommon –she must also accept it and get treatment and "keep living her life". Another woman stated that although she was scared and shocked by her diagnosis, she finally accepted it because she was close to someone living well with the virus (sister-in-law). She reported that, "...she (sister in-law) used to tell me that is not the end of the life. I decide to accept it because there are so many people that I have seen who are living with HIV/AIDS and I told myself, me too I am still going to stay alive." One woman commented on the impact of ART on the manageability and chronic nature of HIV: "So now I have accepted because I noticed that no one is dying if one is taking her ARV's." These scenarios represent a changing tide in HIV acceptance and subsequent disclosure in Cape Town particularly in the light of the impact of extensive and rapid ART availability and accessibility. This is not to discount the nearly universal period of struggle before their disclosure of HIV infection

and the time it takes for one to disclose their HIV status. All of the respondents, except for one person eventually disclosed their HIV status to at least one member of their family, a partner, and friend. The man who reported not having disclosed his status noted that he had a close and supportive relationship with his counselor at the clinic. This man may have felt that his counselor and health care staff more generally provided him with all of the support he needed.

Discussion

For many respondents in this sample, similar to Normon et al's sample, non-disclosure represented a heavy weight or burden on them (9). Similarly, the experience of disclosure often represented a release of this "weight." One participant's mother encouraged her to disclose for this reason. She said, "my mother had said "its better my child that you tell your friends so that you are able to be free (i.e. so that she feels more relaxed and accepting of it) because you won't be free because there is a time that you would get sick, so then at least people should know, you understand." For many, disclosure leads to accessing other supportive spaces such as support, advocacy and activist groups. As Norton et al has pointed out this is clearly related to what Paxton describes as the paradox of disclosure (9). He points out that when HIV-positive people face AIDS-related stigma and don't succumb to it, they eventually find psychological release and liberation from the burden of secrecy and shame (20). These findings support this assertion and further found that over time, many people living with the virus experience significant satisfaction and optimism about having disclosed. It was clear after comparing both temporal trends in each individual interview as well as the

first to second round of interviews that respondents felt more comfortable and free to disclose as time passed. Extensive rollout of ARV treatment over the past few years in South Africa is having a major impact on perceptions of HIV, willingness to disclose one's status and optimism with respect to long life.

All participants found it a difficult process to disclose their HIV status to varying degrees ranging from devastation and/or denial to complete acceptance and a willingness to 'get better'. However, it was overwhelmingly the case that participants felt that the illness was manageable, similar to other chronic illnesses such as diabetes. There seemed to be a common comparison between diabetes and HIV. This comparison was a tool frequently used to manage the personal acceptance and disclosure of the illness. Presumably, there seems to be a vast difference in acceptance of HIV on a community level compared to years past especially in the light of ART. This may be more common in an urban Cape Town setting where social and political mobilisation around HIV and ART literacy and support is widespread and common.

In one of the scenarios described above, one woman's courage to disclose her HIV status resulted in the subsequent disclosure of HIV status to three friends who had been individually hiding their status from one another. This woman's story highlights the complexity of HIV disclosure and the process of negotiation that many people undergo in making disclosure related decisions. Although she struggled with her diagnosis and her eventual disclosure, by the second follow-up interview she eventually felt ready to share. Over the years she gained an immense amount of familial and friend support as a

result of this process. She has since taken on a sense of solidarity with other people in a similar situation. This process represents the 'cost-benefit analysis' many PLWHA go through before disclosing.

Overwhelmingly, family members and close friends were the most supportive in terms of providing material services and emotional support. Men and women were more willing to disclose to their same-sex relative. This has important implications for support services offered by health care providers because it indicates satisfaction and comfort disclosing one's status to someone of the same gender. It seems to be indicative of one's ability to disclose one's status further in the community as well. Furthermore, it seemed to act as a necessary first step in a long process of disclosure to others at a community level. These relatives seemed to represent the 'safe zone' and act as a buffer or a first step in a longer process of potential disclosure to others.

Support groups are an essential component of positive living with HIV/AIDS. However, this was a resource that male respondents did not generally access. There was little information as to why this might be, but it most likely correlates with Nicoli Natrass's findings that women access services and HIV treatment more readily than their male counterparts due to gender norms around accessing ARV's and health services (21). This is despite the fact that the men interviewed were already in the clinic/treatment system but either failed or neglected to access additional psychosocial support systems, especially on a group level. Levels of formal employment among men

as well as gender norms that promote women sharing experiences more than men, may impact on this and need addressing.

Fear or experience of stigma is not the only factor that influences disclosure. There seemed to be generational differences in disclosure with regards to children. Many older women cited their desire to protect their children from harm and worry as reasons for not disclosing to them. Conversely, the younger generation of women interviewed seemed to point out that disclosing to children was important to avoid HIV/AIDS infections in the future. For others, having HIV positive children emphasized the centrality of their child's illness above their own. For example, one woman in her thirties said, "So my life must be around my child, I must give her medication and not stress myself, it is not like I am going to die now. It is like TB and Cancer, so I have accepted HIV; it's within me in my blood." This comment also highlights the manageability and chronicity of HIV as not only a coping mechanism but a tool for strength as a parent and a patient.

Conclusions

I have sought to describe the dynamics of disclosure of HIV infection in clinic settings in Cape Town. For the respondents in this study, the process of disclosure of their HIV status impacted strongly their ability to respond to the implications and effects of the realities of living with HIV/AIDS in the Cape Town context over time.

Disclosure of HIV infection was often seen as a way for HIV-positive persons to regain the freedom and personhood that their HIV-positive status had temporarily taken

from them. Disclosure at a household level was high and resulted in subsequent familial support and reassurance that HIV was not the end of life, given the high prevalence of HIV in local communities. However, non-disclosure at a community level still remains, despite such high prevalence rates, socio-political support and the availability of ART.

While disclosure was a different experience for everyone, many female respondents saw it as an opportunity to become involved in the local HIV community support and at times, activist groups. Men appeared to cope differently, in some key ways. While many disclosed within their families, the diagnosis seemed to have very little impact on their life outside of the household, even with close friends. However, by virtue of the nature of our sample (clinic-based) every respondent had made use of some form of support services that were available at the clinic level.

Moving Forward - "Must a person die because she is afraid of telling another person?"

These findings suggest that in the changing climate of HIV in Cape Town clinic settings, things seem to be easier for both men and women in terms of negotiating the process of disclosure than it was at earlier stages of the epidemic. However, some key recommendations include gender and generational matching for HIV counselors as well as support groups. Expert patient programs are burgeoning in clinic settings but one avenue which may be less explored is family support networks for close family members of PLWHA and those who act as supporters. There is clearly an immense amount of trust confided to those around an HIV positive person, which requires support in its own right.

Gender responsiveness to HIV/AIDS treatment programming is still needed.

While there are a great number of gender focussed prevention programs, treatment programs must reach out to men, especially older men as an important cohort not accessing psychosocial support services. Similarly, women of varying age groups require specialised support and for disclosure to become positive on a community level, these gendered dynamics of disclosure must be addressed in social marketing/media campaigns to facilitate wider community-level disclosure.

Lastly, the availability of ART in this setting has lead to the perception of chronicity and manageability of the virus. This has turned a devastating situation into one that appears manageable and 'chronic' for most in this sample. Overwhelmingly, respondents compared HIV to diabetes, heart disease, cancer and other chronic infections. This is an indication that counselling and support services are working. Patients are receiving the message that HIV is not a death sentence, but an added challenge to life. This is not to understate the severity of the illness or the devastation upon hearing one's diagnosis but to highlight the resilience and courage that many have embodied as this epidemic rages on. It is also an indicator of success for health service providers, policy makers and the immense effort that the NGO community has to 'turn the tide' of HIV. There is still much work to be done to improve the lives of PLWHA and those who are yet to accept their positive status. This study provides some indicators to steps that can enhance disclosure, acceptance and support and highlights the importance of addressing women's greater reluctance to disclose to male partners because of fear of perceived negative repercussions and promoting men's greater

access male counsellors and confidants which could play a role in greater comfort with joining support groups.

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PART D: Appendices



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Human Research Ethics Committee
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Observatory 7925
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23 December 2011

HREC REF: 579/2011

Ms KA Austin-Evelyn,
Public Health & Family
Falmouth Building

CC. A/Prof D Cooper
Public Health & Family Medicine
Falmouth Building

Dear Ms Austin-Evelyn,

PROJECT TITLE: PATTERNS, DYNAMICS AND INFLUENCING FACTORS OF DISCLOSURE OF HIV STATUS AMONG WOMEN AND MEN LIVING WITH HIV IN CAPE TOWN SOUTH AFRICA

Thank you for submitting your new study to the Faculty of Health Sciences Human Research Ethics Committee

It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

Approval is granted until 30 January 2013

Please submit an annual progress report (FHS016) if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file (FHS010).

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR MARC BLOCKMAN

CHAIRPERSON, FHS HUMAN RESEARCH ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

